

Speaking of Mild Mental Retardation: It's No Box of Chocolates, or Is It?

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Abstract:

The meaning of the category and concept of mild mental retardation is explored through the words of fictional characters and the accounts of real people who have been injured and stigmatized by the label. Examples of the extremes to which people have gone to avoid or escape the term *mental retardation* are provided. The classification of mild retardation is presented as a fabrication with no coherence in the characteristics and needs of the people placed under its conceptual umbrella. A call for new terminology and, more important, new thinking about this misunderstood and nearly forgotten population of children and adults is issued.

How does the label *mild mental retardation* influence the feelings and self-esteem of people who are so labeled? For decades investigators have conducted research on this question and have generally reported no direct relation between labeling and self- concept (MacMillan, Jones, & Aloia, 1974). Foxx and Roland (2005), in fact, claimed recently that the "obsession with self-esteem" constitutes a fallacy in educational practice, particularly in special education. This article presents arguments contrary to these reports in relation to the label of mental retardation. The evidence offered consists of the voices of people whose lives bear the impact of the retardation designation and who have struggled with the stigma associated with it. Some of the voices are those of fictional characters, their words based on the perceptive observations of acclaimed writers. Others are the words of real people who give voice to their own struggles with an identity that is not of their own choosing.

The stories and voices presented in this article are intended to provoke questions about the meaning of mild mental retardation and the people to whom the term and concept is assigned. What can or should be done regarding the category, and how can change be executed?

FORREST AND TOM: VOICED PERSPECTIVES ON MILD RETARDATION

The 1994 film *Forrest Gump* was a humorous and yet moving portrayal of a man diagnosed as a child as having physical disabilities and with an IQ that categorized him as mentally retarded. This highly romanticized saga of life with disabilities unfolds with Forrest attending regular public school classes due to the persistence of his mother, his becoming a college football star, his decoration as a Vietnam War hero, his business success yielding millions of dollars, and his becoming a spiritual cult figure. Most important, it depicts him as a sensitive and strong friend, husband, and father.

The most famous line in the movie is in the first scene. Forrest offers a chocolate to a nurse sitting next to him at a bus stop. He explains to her, “My momma always said, life is like a box of chocolates. You never know what you’re gonna get.” In the book by Winston Groom (1986) on which the movie was based, however, Forrest’s reference to a box of chocolates is quite different. It provides a contrasting portrait of his struggle with being classified as retarded.

Let me say this: bein’ a idiot is no box of chocolates. People laugh, lose patience, treat you shabby. Now they says folks s’posed to be kind to the afflicted, but let me tell you—it ain’t always that way. Even so, I got no complaints, cause I reckon I done live a pretty interestin’ life, so to speak.

I been a idiot since I was born. My IQ is near 70, which qualifies me, so they say. Probl’y, tho’, I’m closer to bein’ a imbecile or maybe even a moron, but personally, I’d rather think of myself as like a *halfwit*, or somethin’ not no idiot—cause when people think of a idiot, more’n likely they be thinkin’ of one of them *Mongolian idiots*—the ones with they eyes too close together what look like Chinamen an’ drool a lot an’ play with theyselfs.

Now I’m slow—I’ll grant you that, but I’m probl’y a lot brighter than folks think, ’cause what goes on in my mind is a sight different than what folks see. For instance, I can think things pretty good, but when I got to try sayin’ or writin’ them, it kinda come out like jello or something ...

Now I know somethin’ ’bout idiots. Probl’y the only thing I do know ’bout, but I done read up on ’em—all the way from that Doy-cheeveskie guy’s idiot, to King Lear’s fool, an’ Faulkner’s idiot, Benjie, an’ even ole Boo Radley in *To Kill a Mockingbird*—now he was a *serious* idiot. The one I like best tho’ is ole Lennie in *Of Mice an’ Men*. Mos’ of them writer fellers got it straight—’cause their idiots always smarter than people give ’em credit for. Hell, I’d agree with that. Any idiot would. HeeHee. (pp. 1–2)

The words that Winston Groom has Forrest speak regarding being labeled with the terminology of mental retardation have been spoken repeatedly through fictional characters. They are so numerous and insightful that they constitute evidence of a shared understanding of mental retardation as a label and its consequences by some of the world’s greatest novelists and short-story writers (Halliwell, 2004). They are too numerous to be cited here. One other example of this literary comprehension of the meaning of mental retardation, however, is particularly compelling and illuminating. In a 1916 short story by Jack London, the writer has Tom, a resident of a state mental retardation institution, speak to the reader about his being given a label that is degrading. He also seeks to convince the reader that he is more competent than the label implies.

Me? I’m not a drooler. I’m the assistant. I don’t know what Miss Jones or Miss Kelsey could do without me. There are fifty-five low-grade droolers in this ward, and how could they ever all be fed if I wasn’t around? I like to feed the droolers. They don’t make much trouble. They can’t. Something’s wrong with most of their legs and arms and they can’t talk. They are very low-grade. I can walk, and talk, and do things. You must be careful with the droolers and not feed them too fast ... I am a high-grade feeb. Dr. Dalrymple says I am too smart to be in the Home, but I never let on. It’s a pretty good place. And I don’t throw fits like lots of the feebs. You see that house up there through the trees. The high-grade epilecs all live in it by themselves. They’re stuck up because they ain’t ordinary feebs. They call it the clubhouse, and they say they’re just as good as anyone outside,

only they're sick. I don't like them much. They laugh at me, when they ain't busy throwing fits. But I don't care ... Low-grade epilecs are disgusting and high-grade epilecs put on airs. I'm glad I ain't an epilec. There ain't anything to them. They just talk big, that's all. (pp. 87–88)

Tom also describes several of his fellow residents according to the etiology of their retardation. His description of the characteristics and prognosis associated with each diagnosis is interesting and, in some cases, moving.

Do you know what a micro is? It's the kind with the little heads no bigger than your fist. They're usually droolers, and they live a long time. The hydros don't drool. They have the big heads, and they're smarter. But they never grow up. They always die. I never look at one without thinking he's going to die. Sometimes, when I'm feeling lazy, or the nurse is mad at me, I wish I was a drooler with nothing to do and someone to feed me. But I guess I'd sooner talk and be what I am. (London, 1916, p. 40)

Tom fantasizes about how his life could be improved if the staff of the institution openly recognized his abilities. He believes that if he were treated fairly he could have a “normal” life in the Home.

Some day mebbe, I am going to talk with Doctor Dalrymple and get him to give me a declaration that I ain't a feeb. Then I'll get him to make me a real assistant in the drooling ward, with forty dollars a month and my board. And then I'll marry Miss Jones and live right on here. And if she won't have me, I'll marry Miss Kelsey or some other nurse. There's lots of them that want to get married. And I won't care if my wife gets mad and calls me a feeb. What's the good? And I guess when one's learned to put up with droolers, a wife won't be much worse. (London, 1916, p. 103)

DEBORAH OR EMMA? SEARCHING FOR THE TRUE VOICE

In his 1912 book, *The Kallikak Family: A Study in the Heredity of Feeble-mindedness*, Henry Goddard portrayed a very real young woman he called Deborah as the prototype of his conception of the moron, the term he created for mild mental retardation. He argued that her institutionalization at the Vineland Training School was necessary for her own well-being and for the protection of society. He asserted that if she were released she would almost immediately fall into a life of depravity and promiscuity. He also talked of the positive effects on her life of the institution. He presented pictures of her in the book that displayed not only her handiwork (sewing and woodworking) but also exhibited her attractiveness. According to Goddard, she was thriving and growing because she was institutionalized.

Indeed, Deborah would never be a member of a society other than that of an institution. She was destined to live a total of 81 years in two institutions. From the time she entered the training school until she died at the Vineland State School across the street, she would never know life free of institutional influence. When she died in 1978, she was buried in the institution's cemetery under a marker bearing only her name, her real name, Emma Wolverton.

Descriptions of Deborah subsequent to the publication of the Kallikak study repeatedly referred to her beauty and charm. Edgar Doll worked with Goddard as an assistant from 1912 to 1917 and in 1925 became director of research at Vineland. In 1983, his son Eugene wrote

There is no doubt that, whatever her mentality, she radiated that extra spark of personality which makes one stand out in a crowd and which not only attracts but holds friends. [An eminent American psychologist] wrote urbanely of his first encounter with Deborah—finding her in charge of the kindergarten at the Training School and mistaking her for the teacher. At lunchtime he was surprised to find the same attractive young woman waiting on his table. ...

Time and again visitors in both the Training School and the Vineland State School ... to which Deborah was later transferred, commented on her seeming normality. (p. 30)

Helen Reeves (1938), executive social worker at the Vineland State School, commented on Deborah's transfer from the training school:

For our part we knew we had acquired distinction in acquiring Deborah Kallikak, for by this time the story of her pedigree was becoming well known. And such an able, well trained and good looking girl must be an asset. ... She excelled in the manual arts of embroidery, woodcraft and basketry, played the cornet beautifully and took star roles in all entertainments as a matter of course. She was well trained in fine laundry work and dining room service, could use a power sewing machine and had given valuable assistance as a helper in cottages for low grade children. (pp. 195–196)

As an adolescent, Deborah served in the home of the superintendent of the training school. In addition to performing housekeeping duties, she cared for the family's infant son. She later assumed child care responsibilities for the assistant superintendent of the state school. Children from both of these families continued to visit and correspond with Deborah throughout her life. A woman in one of the families acknowledged her affection and respect by naming her own daughter after Deborah (Doll, 1983).

On occasion, Deborah accompanied the official families to the shore for holidays. Her preference in vacations, however, seems to have been for a series of yearly excursions that she and social worker Reeves took together. Reeves' (1945) recollection of their 1939 autumn trip to Washington, DC, was as follows:

As we rolled along southward I did not realize—though I should have—that I was establishing a precedent and that the succeeding five years would find me doing exactly the same sort of thing at this season of the year. Nineteen-forty would see us at the World's Fair in New York City; Luray Caverns would be visited in 1941 and Niagara Falls the year following; New York City again in 1943, and then—gasoline being scarce and travel facilities constricted—1944 would find us in Philadelphia for those three precious days. (p. 3)

Doll (1983) quoted one acquaintance as saying, "Hers was a body which moved with full knowledge of the impact of its movements on the opposite sex." He goes on to cite the impression of an employee who had accompanied a group of the institution's girls on a boardwalk stroll:

Everytime we passed a man or group of men, they would stop, turn, look after Deborah, and occasionally start to follow us. I do not know what signals Deborah was sending out, but it seemed that one glance from her eyes could summon a following. I was uneasy until we got home, though Deborah had done nothing really fresh or out of order. (p. 32)

While Deborah was serving as a nurse's aide during an epidemic, she stayed in a room near the sick patients. There she was not under the same close supervision of her usual living area. It appears that her woodworking skill enabled her to alter her window screen for easy exit and entry. She had fallen in love with an employee of the state school (apparently a maintenance worker). They seemingly enjoyed the moonlit grounds and each other in a romantic interlude before being discovered. The young man was "kindly dismissed by a lenient justice-of-the-peace" and regulations were tightened for Deborah (Reeves, 1938, p. 196). After a similar experience sometime later, Deborah mourned, "It isn't as if I'd done anything really wrong. It was only nature!" (Reeves, 1938, p. 197). Years afterward, she would again fall in love. Helen Reeves provided some insight into the institutional attitude concerning Deborah's feelings of love and her right to romantic involvement:

In the early fall of 1939 I returned to Vineland after a month's leave to find Deborah's spirits and morale at low ebb. She had worked hard during the summer, trying to do justice to a housework job for one of the official family, keeping on meanwhile with her responsibilities as custodian of the gymnasium and costume room. She had also managed to fall in love while I was away, which romance had been discovered and quietly nipped in full bloom without her knowledge. (pp. 2-3).

How can it be that a woman of considerable talent in several areas of her life, a woman of beauty and charm, a woman lacking in academic skills but able to perform productive work is institutionalized for 81 of the 89 years of her life? When so much of the information that is available indicates that Deborah (Emma) had the potential for living in society, what factors contributed to her lifetime of segregation?

Repeatedly in the accounts of Deborah's life, references are made to her appearance of normality. Visitors and new employees often expressed disbelief when told that she was mentally retarded. Time and again, such skepticism about the validity of classifying Deborah as feeble-minded, as a moron, was countered with the results of standardized intelligence tests. Throughout the available reports, her performance on tests of academic or abstract ability was held to be of greater importance than the obvious strengths she demonstrated in her daily life. All subsequent descriptions echo to some degree Goddard's (1912) summation of Deborah's condition:

Here is a child who has been most carefully guarded. She has been persistently trained since she was eight years old, and yet nothing has been accomplished in the direction of higher intelligence or general education. Today if this young woman were to leave the Institution, she would at once become a prey to the designs of evil men or evil women and would lead a life that would be vicious, immoral, or criminal, though because of her mentality she herself would not be responsible. There is nothing that she might not be led into, because she has no power of control, and all her instincts and appetites are in the direction that would lead to vice. (11-12)

Goddard (1912) eventually tempered his thinking on the issue of the unmodifiable nature of mild mental retardation, on the incurability of the moron. Deborah, however, would be affected by the legacy of the original diagnosis for the rest of her life. Perhaps the greatest tragedy was that Deborah came to believe that life in an institution was the only one possible for her. In 1938, she

told Helen Reeves, “I guess after all I’m where I belong, I don’t like this feeble-minded part but anyhow I’m not i-idic like some of the poor things you see around here” (Reeves, 1938, p. 199).

In 1945, Reeves reported that “Deborah, in spite of her conscious superiority, does not feel secure away from the institution. ... ‘The world is a dangerous place,’ she will tell you” (p. 2).

Deborah was in a wheelchair during her final years. She was often in intense pain because of severe arthritis and was unable to continue the crafts she had loved throughout her life. In her last years, she was offered the alternative of leaving the institution to live in the community she had been denied most of her life. She declined the opportunity. She knew she needed constant medical attention (Smith, 1985). Emma Wolverton had also come to believe deeply the story that had been told to her in the name of Deborah Kallikak.

The book, *Mother, Can You Hear Me?*, by Elizabeth Cooper (1983) is the story of a psychologist who searches for her birthmother. This journey leads her to the discovery that her mother was deaf, had been misdiagnosed as mentally retarded, and had been institutionalized. In the book Cooper speaks of her internship in psychology at the State School at Vineland and her relationship with Emma Wolverton:

Sometimes I felt as though I were one of the residents in the small barren institutional room where I spent my nights and several weekends. Emma was one of the residents, and she had interesting stories to tell me. Her job was to do some of the hand ironing, and she had been allowed to set up a small space like a tiny apartment for herself. She was very friendly toward me. From her I learned firsthand about the classic study of two branches of the Kallikak family, from which she was descended ... She was devoted to the people who conducted the study, as though they were her family. Test results found her to be retarded, but I found her to be informative and interesting to talk with. She was considerate and personable and certainly not what I would think of as a retarded person ... Emma was tall and reticent in her manner. She reminded me of anyone’s elderly aunt ... The people who [studied] her wanted to show a genetic basis for her mental deficiency. They traced her roots back to Revolutionary War days—she could have belonged to the D.A.R. ... Emma was taken into her training school at an early age and, I believe, “trained” to fulfill the prophecy of deficiency. (p. 79)

Indeed, she had been trained to think of herself as deficient, she and thousands of others in America’s schools and institutions.

THE STATE SCHOOL BOYS: THE LABEL AND THE REBELLION

Orphaned and then left alone by the death of his foster mother in 1949, 8-year-old Freddie Boyce was given an IQ test. On the basis of this one test score he was sent to the Fernald State School in Massachusetts. He and other children like himself who were diagnosed as having mild mental retardation (feeble-mindedness) were denied appropriate educational opportunities and were frequently abused. There were repeatedly told by staff members of the institution that they were incapable and incompetent.

In his book, *The State Boys Rebellion*, D’Antonio (2004) described the humiliation that Freddie, and other boys who had been committed to Fernald under similar circumstances, experienced:

By the time they were ten or eleven, the State Boys understood that nearly everyone on the outside considered them to be “retards.” This word hurt them as much as the word “nigger” hurt blacks. When they were angry they flung it at each other.

Attendant McGinn reduced boys to tears by calling them retards as they waxed the floors and buffed them ... More than one would recall, as adults, how McGinn whispered into their ears that they were “worthless” or “stupid” and that “no one gives a shit about you.”

Another bit of torture, which McGinn began to use after Freddie had been at the [institution] for a couple of years, was reserved for those who talked during meals in the downstairs dining room. He would grab a slice of bread from the boy’s tray and tear off enough to wad into a ball the size of a large marble. He would then yank the boy to his feet, and tell him to get down on the floor and push the bread with his nose. McGinn would laugh and say, “Look at the retard.” (p. 77)

After hearing these words of belittlement and degradation so often from authority figures, some of the boys began to believe they were true:

The humiliation and constant name-calling—retard, lifer, moron—were difficult to ignore. This barrage beat down Albert Gagne until he began to believe that he *was* defective and destined to spend his entire life inside the institution. He became more and more withdrawn from the other boys. (D’Antonio, 2004, p. 78)

Others of the boys, however, resisted and challenged the derogatory labels with which they were constantly bombarded. Usually their challenges did not lead to changes in their status, even when the facts uncovered through their challenges belied the names they were being called and the necessity for their being institutionalized. The experience of Joey Almeida illustrates this futility.

Every act of defiance was a challenge to the “retard” label. In a few rare cases, these challenges worked, and some on the Fernald staff were forced to recognize that a diagnosis or assessment might be wrong. Soon after he was admitted, Joey Almeida began insisting that the state had gotten his age wrong, that he was really 10, not 11. In a meeting with a social worker, he was so adamant that the social worker finally agreed to look it up. It turned out that Joey was right.

Intrigued by the way Joey had calmly asserted himself in conversation, the social worker gave him a new IQ test. In his subsequent report, he wrote that he found “no real evidence of this boy being significantly retarded, particularly to a degree that requires institutionalization.” Joey’s problem

Seems to be emotional rather than his being retarded ... if guided correctly, in a place other than Fernald, he would have a better opportunity in life.” Nothing was done in response to this report. Joey remained in Fernald, in the Boys Dormitory, perpetually worried that the daily taunt—You’re a lifer—was his fate. (D’Antonio, 2004, pp. 82–83)

The State Boys were inspired by radio and television reports about the Civil Rights Movement. This led them to protest their verbal and physical abuse by the staff and even their institutionalization at Fernald. After pleading for better treatment to no avail, they ran away. Caught and brought back, they seized control of their ward and demanded that their rights be

recognized. Although they were imprisoned and otherwise punished for their actions, they were eventually released to fend for themselves.

Although there were tragic life stories for some of the State Boys, others managed to build strong and productive lives for themselves after leaving Fernald. In the late 1990s they became aware through news coverage that they had been used as human guinea pigs while at the institution. They had been fed radioactive oatmeal as part of an experiment on the physiological effects of radiation. This brought the boys together again and they sued the State of Massachusetts and won a multimillion-dollar settlement (D'Antonio, 2004).

MONTGOMERY'S WISHES

Although mild mental retardation is not always associated with Down syndrome, the following is the account of a young man who had many skills that would place him in that category. It is a personal story as well and I have told it before (Smith, 2003). It taught me much about the impact of words and unsettling restrictions on the life of a person with a disability.

His name was Montgomery. Of the many people I have known with Down syndrome, he was the most verbally talented. I first met him at a sheltered workshop. He worked there, and I served on the board. Later, I invited him to attend a weekend respite camp for people with disabilities staffed by my undergraduate college students. He charmed and amazed them for 3 days with his jokes and stories.

Montgomery was well aware of the stigma associated with the term *mental retardation*. He also clearly understood the term Down syndrome and its implications for him. He seemed to be laboring constantly to convince everyone that he was not mentally retarded. From the beginning he made it evident that he did not need help or supervision during the camping weekend. Within a few hours of arriving, in fact, he asked to be given a job as a counselor. He explained that he would help the college students assist and supervise the "handicapped people" at the camp. His request was granted, and he served as a counselor with distinction throughout the weekend.

Later in that college semester, I asked Montgomery to visit one of my classes. He agreed to talk about his experiences as a child, adolescent, and young adult. He spoke candidly with the students about the impact of the stereotypes of mental retardation and Down syndrome on his life. He also spoke openly about living with a mother who would not, from his perspective, let him live an adult life. He felt she was treating him like a child even though he was 27. His younger brother was living on his own and doing the things Montgomery wanted desperately to do as a young adult.

That evening after class I drove Montgomery home in my car. On the way he asked if we could stop at a Seven-Eleven. In the parking lot he insisted that I wait in the car while he went in for a soft drink. After a few minutes he returned with a Coke for each of us. Soon I delivered him to his front door. His mother greeted us with a glance at her watch. She had apparently been listening for the car, and she made it obvious that she thought we were a bit late.

The next day Montgomery's mother called me at my office. She was disturbed. She had just discovered a pack of cigarettes and a Playboy magazine in his room. She demanded an

explanation. I told her that I could only assume that Montgomery had bought both at the Seven-Eleven while I waited in the car. She was furious that I had allowed this to happen.

After several months and numerous apologies and assurances that there would be no further Seven-Eleven stops, Montgomery's mother agreed to allow him to speak with another of my classes. During the ride to the college Montgomery complained to me that he wasn't being treated as an adult by his mother. He cited again his younger brother as an example of the rights and privileges of adulthood that he longed for. His brother rode a motorcycle; Montgomery was not even allowed to ride as a passenger. He wanted more than anything to experience the feeling of freedom that he imagined riding a motorcycle would give him.

Montgomery talked with my students that evening about his recollection of being in special education classes as a child. He also talked about his experiences at the workshop. He answered each of their questions with care. His observations and reflections were, as always, provocative. My most vivid memory of that evening, however, is of the last question he answered. One of my students asked him what his wishes would be if he had three. Montgomery paused briefly and then replied that he wanted four wishes.

"My four wishes," he said, "are to ride a motorcycle, smoke cigarettes, look at Playboy if I want to, and not be called retarded."

Along with my students, I was stunned by Montgomery's remarks. Regardless of the wisdom or political correctness of his choices, all of us were moved by his message of a yearning for freedom and a wish to escape the stigma of a term and concept that were dominating forces in his life. Almost immediately I was lost in thoughts of race and racism, gender bias, and the many devastating stereotypes that pollute our social relationships.

Montgomery's wish to free himself from the label of mental retardation has been found to be shared widely by those to whom it has been assigned. In an important study and excellent review of the literature, Finlay and Lyons (2005) found that escape from being labeled in this manner is a common quest for those who are asked for their own opinions of the diagnosis of mental retardation that has been assigned to them by others.

ESCAPING THE LABEL AT ALL COSTS: GLEN RIDGE

In 1989 a group of male high school athletes in the affluent town of Glen Ridge, New Jersey, were accused of sexual assault of another student. She was assaulted with a broom handle, stick, and baseball bat. The young woman was labeled as mentally retarded. Rape charges were brought against seven of the young men. When the victim was called on for testimony, one of the attorneys defending the accused young men said to her that some people thought of her as having mental retardation. She agreed, saying, "Lots of kids in school said that." But she also agreed when he said that she "was proving [herself in court to be] ... not retarded." His intent was to show that her performance as a witness was evidence that she was not retarded and therefore that she had not been taken advantage of by the boys. She supported his argument by saying, "If I was retarded, I could never answer all these questions" (Haney, 1992, p. 36). More important to her than the conviction and punishment of those who had assaulted her was to be seen as

competent and articulate. She was driven by the wish to escape the label and to be accepted as a “normal” person.

In spite of her struggle to prove her competence, however, the victim of the Glen Ridge rape became the person she had been labeled to be in the judgment of the court and others. Expert witnesses, her family, and others who testified portrayed her (in support of the charges against her rapists) as fitting the stereotype of mental retardation. She was described as defective, weak, and unable to protect herself. And so the price of justice in her case was the loss of the identity she craved, to be “normal” instead of “retarded.” In the words of one of her convicted abusers, “I now understand ... how sick she really is, and I just feel great feelings of guilt and shame and I wish nothing had ever happened” (Lefkowitz, 1997, p. 162). Even though her articulate testimony was central to the conviction, she had become to her rapist and others a subject of pity, a person “sick” with retardation.

MENTAL RETARDATION: IT’S LIKE A BOX OF CHOCOLATES. YOU NEVER KNOW WHAT YOU’RE GONNA GET

In 1992, the American Association on Mental Retardation (AAMR) listed more than 350 conditions in which mental retardation occurs. This list of causes does not, of course, take into account the varying degrees of retardation or other disabilities associated with each of the etiologies. When those variables are considered, the universe of human conditions subsumed under the term *mental retardation* is overwhelming. The staggering list of causes of mental retardation illustrates the allure and power of typological thinking. This is the belief that complex individual variations can be reduced to underlying human types or essences. Stephen Gelb (1997) found that definitions of mental retardation, regardless of their particulars, are grounded in typological thought.

The term *mental retardation* has been used to describe people who are more different than they are alike (Gelb, 1997). It has been used as an amalgam for very diverse human conditions. The core of mental retardation as a field is the assumption that somehow there is an “essence” that eclipses all of the differences that characterize people described by the term. It is truly a box of chocolates; however, “you don’t know what you’re gonna get” when you reach into the category. Maybe it will be someone who needs constant care, or maybe it will be someone much like yourself but who needs help with academic skills. Maybe it will be someone with severe physical disabilities, or maybe it will be someone you would pass on the street without notice.

What is certain about the category is that it is a stigmatizing label with universally negative connotations. That may be the only “glue” that holds it together. According to James Dudley (1997), people with the label, particularly those with the mild mental retardation designation, find that they are not even embraced as part of the disabilities rights movement in the United States. A perspective on the meaning of the term *disability* that has been articulated in recent years is that the definition must be changed in a very fundamental way. Said Triano and Obara (2003), “I define disability as a natural and beautiful part of human diversity that people with disabilities can take pride in” (p. 3). Listening to the voices of people with the mild mental retardation label, it is hard to imagine how they could see it as “natural and beautiful.” Triano and Obara, in fact, acknowledged that a person with a “cognitive disability” is likely to be “excluded and left out” of the disabilities rights movement (p. 2). Speaking of the special

difficulties faced by people with mental retardation in becoming part of the movement for self-advocacy and civil rights they said

Hannah Arendt once said that “the most radical revolutionary will become a conservative the day after the revolution.” Since its founding, the disabilities rights movement in the U.S. has served as a strong voice for radical revolutionary change. But no radical revolutionary force can remain so as long as it refuses to constantly evaluate itself and adapt according to the demands and needs of the changing times. When the strategies we use start to exclude and offend key segments of our community, allow participation by only those privileged members who can afford to participate, and rely on a tactic of secrecy to the point where it becomes an access barrier for members of our community with cognitive and other disabilities, then we have ceased to be radical and revolutionary. (p. 3)

CHANGING NAMES OR CHANGING MINDS?

There has been much discussion and some action in recent years regarding the use of the term *mental retardation*. Mental retardation has been questioned as both a concept and as a description. It has been called a myth (Smith, 2002). On the other hand, caution has been advised in changing the terminology of mental retardation given the potential funding and service implications of a major change (Luckasson & Reeve, 2001). Changes in language are already evident in the titles, policies, and mission statements of a number of organizations (The Arc, 2004; Stodden, 2002). The board of directors of the AAMR has voted to change the name of the organization to the American Association on Intellectual Disabilities, and this change will soon be presented to the membership for a vote (Warren, 2003). A change in terminology is a move in a very positive direction. Mental retardation is the most stigmatizing of the disability labels, and laundering the term itself of its stigma is impossible; it has had too many negative connotations for too long. People who have been labeled with the term *mental retardation*, and their families, should be asked how they wish to be known. Dudley (1997) pointed out that other minority groups have determined for themselves how they wish to be known and when changes in language about them should be made (e.g., the historical changes in terminology from Negro, to Black, to Afro-American to African American). Mental retardation must become only an historical term, and yet changing the label alone will not serve the people currently categorized as mildly mentally retarded very well. Some would say that it would make no difference at all, because the term *mildly retarded* was eliminated by the AAMR in 1992 in favor of classification on the basis of level of need rather than level of severity. A survey of states, however, indicated that the AAMR definition has had little impact on the classification of mental retardation (Denning, Chamberlain, & Polloway, 2000) and thus that mild retardation and its other signifiers (e.g., educable mental retardation and educable mental disability) are alive and used widely. Changing our thinking about people is more important than what we call them.

Polloway (2004) has discussed the dramatic decreases in the numbers of students classified and served within the category of mental retardation. He pointed out that the prevalence rates for mild retardation have declined from more than 2% of the school-age population in the 1970s to prevalence rates for mental retardation overall in some states that are so low as to preclude any students with mild retardation. He went on to explore the language of mild mental retardation and provided direction for reconceptualizing the needs of students formerly categorized in this manner:

It can be argued that the concept of “mild retardation” itself represents an oxymoron that, perhaps for this reason alone, results in its need to be stricken from the professional vocabulary. As an option, the term *high incidence disabilities* reinforces the fact that there are a relatively large number of students who have learning needs that traditionally have been associated with mental retardation but that these learning needs are incorrectly captured by the term *mild*. Thus, high incidence can be seen as a fact, whereas mild is a *judgment*. (p. 8)

It is widely recognized that changes in the field of special education have had a direct and causative influence on the numbers of students in the mild retardation category and on the interest and resources invested in the field. Many of the students who would have been so designated and served a generation or two ago are now served in learning disabilities contexts. Unfortunately, there has also been a “forced migration” of many of these students from special education into a neverland of no service at all. It is not uncommon to find significant numbers of students who are unofficially considered to be simply and unquestionably “slow learners” not eligible for special education. Many special educators, including myself, have stood by in relative silence while many of these students have been “disenfranchised” from special education. Inordinate numbers of these students are, of course, children and adolescents from poverty, minority, and language-disadvantaged backgrounds.

Polloway (2004) asked whether the time has come for a eulogy for the field of mild mental retardation. I think he then answered his own question. Yes, the term is dead and deserves a decent burial. But no, we cannot allow a recognition of the needs of numbers of children and adults to “pass away.” It is incumbent on the many of us who began our careers in the field of mild retardation that we strive to rekindle interest in and commitment to the students who have escaped a negative identity but who are now adrift with little help for their significant learning needs.

Thus, in our appropriate efforts to downplay the deficits associated with mental retardation and emphasize the importance of a supports-based model, we may lose sight of the educational and life needs of persons traditionally identified as having mild retardation. The movement to inclusion is admirable, but a parallel commitment to ensuring the success of these individuals is also essential ... the question is unanswered as to whether the passing of this category is best classified as lack of interest, lack of awareness, or deliberate attempts to bring about its demise. Regardless of cause, it is important that we continue to focus on making sure that these students will not be disadvantaged by our ignorance of their educational needs. (Polloway, 2004, p. 8)

The time is overdue for professionals, professional organizations, parents, self-advocates, and others to reinvigorate the dialogue, engage in the research, and push for the funding that will bring new life to the field that gave birth to special education. This is the legacy of Jean Itard, Maria Montessori, Elizabeth Farrell, Lloyd Dunn, Sam Kirk, and others who saw potential and possibilities where most educators saw obstacles. Even more important than changing a names is changing our minds, and the minds of others, about a nearly forgotten population of children and adults.

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